

GETTING WHAT YOU NEED WHEN YOU NEED IT: PROGRAMS AND SERVICES THROUGHOUT THE LIFE CYCLE

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An often bewildering array of programs, services, and agencies exist to provide support to individuals on the autism spectrum at the different stages of life from birth through adulthood. This article will provide an overview of what they are, what services they provide, how to get them, and what to do if eligibility or services are denied. It is not intended to be an exhaustive discussion of the subject, but to offer important basic information.

I. EARLY INTERVENTION—BIRTH TO THREE

What is it?: Children with disabilities from birth to age three are covered under Part C of the Individuals with Disabilities Act, (“IDEA”), a federal law. Every state has a “Child Find” responsibility under the IDEA that requires it to look for children who may have disabilities and need early intervention or special education services. The state educational system has primary responsibility for this, and must refer any children it identifies to the appropriate agency. In Pennsylvania, it is the Department of Public Welfare that is primarily responsible for provision of services for infants and toddlers, operating through the Office of Childhood Development and Early Learning (“OCDEL”).

Who is eligible for it?: A child under the age of three qualifies for Part C services if the child is experiencing a “developmental delay” in one or more of the following areas of development: cognition, physical (including vision and hearing), communication, social or emotional, or adaptive (self-help skills), or has a physical or mental condition that has a high probability of resulting in such a delay. In Pennsylvania, the standard for finding a developmental delay is a 25% deviation from the norm in any one or more of those developmental areas. Children transition to age three to five services (see below) on their third birthdays.

What services can it provide?: Services are provided under an Individualized Family Service Plan (“IFSP”) developed by a team that includes agency personnel and the parents. The IFSP is based on an evaluation of the child and her needs. Services are free, are to be provided in the child’s natural environments (which often includes the home) to the maximum extent appropriate, and include, among others, assistive technology, audiological services, family training, counseling, home visits, health services, evaluation services, nutrition services, nursing services, occupational therapy, physical therapy, speech therapy, social work services, specialized instruction, psychological services, vision services,

transportation and related costs. The IFSP must be reviewed at least once every six months.

How can I get them?: Families can apply for Part C services through their county's early intervention program or by calling the CONNECT Helpline at 1-800-692-7288.

What can I do if services are denied?: If services are denied in whole or in part, parents can challenge the denial through the Early Intervention Complaint Resolution Process ("EICRP"), which allows complainants and OCDEL advisors to try to resolve the issue without resorting to a formal complaint or a formal hearing process. Families can write to OCDEL at 333 Market Street, 6th floor, Harrisburg, PA 17126-0333, or fax a complaint to 727-346-9320. Alternatively, or if that doesn't successfully resolve the complaint, a formal complaint can be filed with the agency, or a due process hearing instituted through the Office for Dispute Resolution, odr.pa.org. However, while prevailing parents in due process hearings under Part B of the IDEA can usually recover their costs and attorneys' fees, (see below), prevailing parents under Part C cannot, which can make due process a relatively expensive option.

II. EARLY INTERVENTION—THREE TO FIVE

What is it?: Children with disabilities from age three through five are covered under Part B of the IDEA. Every state has a "Child Find" responsibility under the IDEA that requires it to look for children who may have disabilities and need early intervention or special education services. The state educational system has primary responsibility for ensuring this. In Pennsylvania, services are provided through agencies known as "MAWA" holders. In most cases, those agencies are the local intermediate units, but not always. For example, in Philadelphia the MAWA holder is Elwyn, Inc.

Who is eligible for it?: A child from ages three to five in Pennsylvania qualifies for Part B services if the child has a listed IDEA disability or is experiencing a 25% developmental delay in one or more of the following areas of development. The listed IDEA disabilities are autism, emotional disturbance, hearing impairment, intellectual disability, orthopedic impairment, other health impairment, specific learning disability, speech and language impairment, traumatic brain injury, and visual impairment. Parents may opt to have their children spend an additional year in early intervention, transitioning to school district services when their kids are six, rather than when they are five. Six year olds must transition at the start of the school year after the one in which they turn six.

What services can it provide?: Services are provided under an Individualized Education Program (“IEP”) developed by a team that includes agency personnel and the parents. The IEP is based on a free, comprehensive evaluation of the child and his needs. Services are based on educational necessity, are to be provided in the least restrictive environment (“LRE”) to the maximum extent appropriate, and are intended to provide the child with a free, appropriate public education (“FAPE”), including where necessary related services like speech therapy and occupational therapy. LRE is defined in the IDEA, and means the amount of time children with disabilities spend with their non-disabled peers. It is very clear that Part B early intervention services can be provide in typical preschools. There is a split of legal authority on whether the MAWA holder is required to pay for the typical preschool itself.

How can I get them?: Families can apply for Part B services through the MAWA holder (usually the IU) or by calling the CONNECT Helpline at 1-800-692-7288.

What can I do if services are denied?: Parents must be provided with prior written notice whenever the MAWA agency proposes to initiate, change or deny a service. If services are denied or inappropriate in whole or in part, parents can challenge the denial through a request for mediation or for a special education due process hearing through the Office for Dispute Resolution. The ODR website, odr-pa.org, has the complaint forms for initiating either mediation or a due process hearing. Parents at mediation can be accompanied by advocates, but not by lawyers. At mediation, a trained mediator attempts to get the parties to reach a mutual agreement, but does not issue a decision or determine an outcome. Due process hearings are presided over by impartial administrative hearing officers, who hear the evidence and who render an enforceable decision. Parents can (and whenever possible, should) be represented by attorneys at hearing. Prevailing parents in due process hearings under Part B can usually recover their costs and attorneys’ fees. Alternatively, parents can file an informal administrative complaint through the Early Intervention Complaint Resolution Process (“EICRP”), which allows complainants and OCDEL advisors to try to resolve the issue without resorting to a formal complaint or a formal hearing process. Families can write to OCDEL at 333 Market Street, 6th floor, Harrisburg, PA 17126-0333, or fax a complaint to 727-346-9320, or by filing a formal complaint with the Pennsylvania Department of Education.

III. SCHOOL-AGED SERVICES—FIVE TO TWENTY-ONE

What are they?: Children with disabilities who are school-aged and who require specially designed instruction are covered under Part B of the IDEA, and are entitled to appropriate special education and related services provided under

the auspices of their local education agency (“LEA”), usually their local school districts or a charter school.

Who is eligible for them?: A student with a disability who requires specially designed instruction is eligible for school-aged IDEA services from the start of the school year after the one in which she turn five (or, at parental option, six) through graduation, completion of all IEP services, or the end of the school year in which she turns twenty-one, whichever is earlier. The student must have a disability listed in the IDEA: autism, emotional disturbance, hearing impairment, intellectual disability, orthopedic impairment, other health impairment, specific learning disability, speech and language impairment, traumatic brain injury, and visual impairment. There is no school-aged category for developmental disability.

What services can they provide?: Services are provided under an Individualized Education Program (“IEP”) developed by a team that includes LEA personnel and the parents. The IEP is based on a free, comprehensive evaluation of the child and her needs. Services are based on educational necessity, are to be provided in the least restrictive environment (“LRE”) to the maximum extent appropriate, and are intended to provide the child with a free, appropriate public education (“FAPE”). LRE is defined in the IDEA, and means the amount of time children with disabilities spend with their non-disabled peers. Services include specially designed instruction and related services, as well as supports for school personnel.

How can I get them?: Families can apply for Part B services through their local LEAs.

What can I do if services are denied?: Parents must be provided with prior written notice whenever the LEA proposes to initiate, change or deny a service. If services are denied or inappropriate in whole or in part, parents can challenge the denial through a request for mediation or for a special education due process hearing through the Office for Dispute Resolution. The ODR website, odr-pa.org, has the complaint forms for initiating either mediation or a due process hearing. Parents at mediation can be accompanied by advocates, but not by lawyers. At mediation, a trained mediator attempts to get the parties to reach a mutual agreement, but does not issue a decision or determine an outcome. Due process hearings are presided over by impartial administrative hearing officers, who hear the evidence and who render an enforceable decision. Parents can (and whenever possible, should) be represented by attorneys at hearing. Prevailing parents in due process hearings under Part B can usually recover their costs and attorneys’ fees. Alternatively, families can file a formal complaint with the Pennsylvania Department of Education.

IV. TRANSITION SERVICES—AGES FOURTEEN THROUGH TWENTY-ONE

What are they?: Students with IEPs who will turn fourteen during the course of the IEP year are entitled to transition plans as part of their IEPs. Transition plans are intended to map out a path from school to adulthood and to provide the student with the opportunity to acquire the skills necessary for adult life. They cover, at minimum, the areas of post-secondary education and training, employment, and independent living.

Who is eligible for them?: A student with an IEP who will turn fourteen during the course of the IEP year must have a transition plan as part of that IEP and every subsequent IEP through graduation, completion of all IEP services, or the end of the school year in which the student turns twenty-one, whichever is earlier.

What services can they provide?: In addition to the IEP services potentially available to all school-aged students, the transition plan can include a broader range of services. These may include on-site job training or coaching, provision of counseling, vocational evaluation, assistance in finding competitive employment, enrollment in supported employment or sheltered workshops, assistance in pursuing higher education, college preparation, skills in activities of daily living, community living skills, and assistance in accessing the services available from other governmental agencies in adulthood. The transition plan also must include linkages to the service delivery systems available to the student upon transition from school-aged services. The LEA remains primarily responsible for seeing to it that those linkages occur. The transition plan broadens the focus of a free, appropriate education to embrace home and community skills.

How can I get them?: Transition plans are developed by the student's IEP team at the regular IEP meeting.

What can I do if services are denied?: Mediation and due process hearings are available for transition service disputes as they are for all other school-aged IEP-related disputes. (See above for details).

V. PRIVATE HEALTH INSURANCE—ACT 62

What is it?: Act 62 is a Pennsylvania statute requiring private insurance companies to pay up to \$36,000.00 per year for diagnostic assessments and medically necessary treatment of covered children under 21 years old who have autism spectrum disorder.

Who is eligible for it? Children under 21 who have autism spectrum disorder and are covered by a group health insurance policy that is not self-funded and that covers 51 or more employees, or who are enrolled in the Pennsylvania CHIP program, are eligible.

What services does it provide? Services include medically necessary diagnostic assessment, psychiatric care, psychological care, therapeutic care (including speech, occupational, and physical therapy), and pharmacy care. They include applied behavior analysis, behavioral specialists, mobile therapists, and therapeutic staff supports. The services must be identified in the individual's treatment plan and prescribed and provided either by certain licensed professionals or by autism services providers.

How can I get them? Your service provider submits the bill for services to your insurance carrier. If your child is eligible for Medical Assistance (see below) and your private insurance has a deductible or a co-pay, be sure that your provider bills Medical Assistance for that directly. You cannot pay it yourself and be reimbursed by Medical Assistance.

What can I do if services are denied? There is a grievance procedure required under Act 62 for denial of services. Insurers are required to use expedited internal and external review procedures for such grievances. You can file a request for expedited internal review with the insurance company, and the company must issue a decision within 48 hours of receiving the request. Within two business days of receiving an unfavorable ruling on the internal review, you can request an expedited external review, which must forward the request to the Pennsylvania Insurance Department within 24 hours of receipt. Within two business days of receiving the request for external review, the Insurance Department will assign a Certified Utilization Review Entity ("CRE"), who will review the decision and issue a ruling within two business days after it receives the assignment. If the CRE overturns a denial or partial denial of services, the private insurance company can file an appeal in state court. The company must pay for the services authorized or ordered pending a ruling by the court. If the CRE upholds the denial of services, you can still seek them through Medical Assistance.

VI. MEDICAL ASSISTANCE

What is it?: Medical Assistance ("MA") is a program of public health insurance for individuals who are either medically needy or categorically needy. It pays for medically necessary services, and is a "payer of last resort", kicking in after private insurance limits have been reached.

Who is eligible for it? Medical Assistance eligibility for adults is based on income and resources. Adults receiving SSI (Supplemental Security Income) are generally eligible for Medical Assistance. Children under 21 with disabilities in Pennsylvania are covered under the “loophole”, which does not consider family income and assets in determining eligibility. However, the child’s own income in his own name is considered. A child is considered to be potentially eligible if she has a physical or mental condition that very seriously limits the child’s activities, that has lasted or can be expected to last more than a year or to result in death. There has been much talk lately about requiring either a premium payment or co-pays based on family income for “loophole” kids, but so far it has not happened. As of this writing, a premium is more likely to be on the horizon than a co-pay. People with disabilities who work part time and who make too much money to get free MA can often purchase Medical Assistance for Workers with Disabilities (“MAWD”) insurance, where the income limits are much higher than for traditional MA.

What services does it provide? Any medically necessary service can be covered under MA. Almost all medical services for children are likely to be covered under Early Periodic Assessment, Diagnosis and Treatment (“EPSDT”). MA is also the source for waiver funding (see below).

How can I get them? Application for MA is made through the local County Assistance Office (“CAO”). Families who are applying for their kids with disabilities, not based on financial need, can use the Simplified Application, PA600-CH, which requires the provision of far less information about family finances.

What can I do if services are denied? You must receive written notice of any denial of services, and the written notice must include information about what was denied, the reasons for the denial, and how to appeal the denial. You can request a Fair Hearing from the Department of Welfare within 30 days of the denial. For managed care plans (almost all MA plans in this region, and all behavioral health plans), you can also file a grievance or a complaint. A First Level grievance is a hearing, usually by telephone, with essentially the same people who denied the services in the first place. However, since you have the opportunity to provide additional information supporting the need for the denied services, it can be effective. If that doesn’t work, you can file a Second Level grievance, heard by a panel of individuals, some of whom have not previously been involved in the case. If that still doesn’t work, you can file a request for a Fair Hearing. If MA is proposing to cut services your child is already receiving, you can preserve them during the course of this process by filing the grievances and/or requesting the Fair Hearing at each stage within ten days of the notice of denial.

VII. WAIVERS

What are they?: Waivers are sources of funding under MA that provide for kinds of services that MA does not otherwise usually cover, such as respite services, habilitation for adults (as opposed to rehabilitation, which is covered), and home and vehicle modifications, to name a few. Waivers are not an entitlement, and even eligible individuals can be denied waivers, which are limited in the number of people they serve and/or by the amount of money available. Waivers are intended to help provide the supports necessary to keep people with disabilities in their homes and communities, and out of institutions.

Who is eligible for them? We are dealing with two primary types of waivers: intellectual/developmental disability waivers and autism waivers. There are income and resource limitations for all waivers which vary depending on the kind of waiver being sought. Individuals with these disabilities who receive MA are potentially eligible and should apply. However, because of limited availability, eligible applicants will likely be placed on waiting lists, which can be quite long. Eligible individuals for intellectual/developmental disability waivers will be assigned a place on the “PUNS List” depending on the urgency of need: emergency (needing immediate services within the next six months); critical (needing services in more than six months but less than two years); and planning (needing services in more than two but less than five years). There are waiting lists even for those in the emergency and critical categories.

There are two kind of intellectual/developmental disability waivers: Consolidated Waivers and Person/Family Directed Waivers. Both require that the applicant be registered for I/DD services in his county. They also require that the individual have a completed IQ test by someone qualified to give it with an IQ score of 70 or lower (clinical judgment may apply), have a completed Adaptive Behavior Scale (“ABS”) showing deficits in two or more areas of adaptive functioning, and have a record of MR diagnosis prior to the age of 22 signed by a licensed clinician or certified school psychologist.

The Adult Autism Waiver, administered through the Pennsylvania Bureau of Autism Services, is potentially available to MA-eligible individuals 21 or older who have a diagnosis of autism spectrum disorder and who have functional limitations evident before age 22 and likely to continue indefinitely in three or more major life activities: self-care, understanding and use of expressive and receptive language, learning, mobility, self-direction, and capacity for independent living. Applicants will be assigned a Priority 1 or 2. Priority 1 is for those not currently receiving state-funded or state and federally-funded home and community-based services, and Priority 2 is for those who are. No applications will be sent to Priority 2 folks until all Priority 1 applications have been processed. Waiting lists are long.

What services do they provide? The Consolidated Waiver is a source of funding to support community living that has no absolute dollar limit. It can be

used for supports coordination, unlicensed residential home and community habilitation, companion services, respite services, homemaker/chore services, day services, prevocational services, supported employment services, transitional work services, transportation, educational support services, specialized supplies, nursing services, therapies, behavioral support, home accessibility adaptations, and assistive technology. It can also be used for licensed residential habilitation. The Person/Family Directed Support Waiver is currently limited to \$26,000.00 per year, and can be used for most of these as well, but cannot be used for licensed residential habilitation.

The Adult Autism Waiver provides funding for long-term services and supports for community living, tailored to the specific needs of the individual with ASD. Services include assistive technology, behavioral support services, community inclusion and transition services, day habilitation, family counseling and training, environmental modifications, job assessment and finding, nutrition counseling, residential habilitation, respite, supported employment, therapies, and transitional work services. It can pay for 24/7 care in the community if a need is determined through assessment.¹

How can I get them? Application for Intellectual/Developmental Disability Waivers are applied for through the county Supports Coordinator or by filling out a Waiver Application/Service Delivery Preference Form (DP 457) and delivering it to the County Office.

Application for Adult Autism Waiver is made through the Bureau of Autism Services by calling 866-539-7689. Applications may not be requested by email and are not available on line.

What can I do if services are denied? Individuals denied eligibility for intellectual/ developmental disability waiver funding or denied services under waivers they are receiving have a right to appeal and request a Fair Hearing from the County Office. Requests should be in writing and filed and received within thirty calendar days of the date the written notice of denial was mailed (not the date on which you received it). You can also appeal by telephone, as long as you follow up with a written hearing request within three days. If you did not get a written notice of denial, you have six months from the date of the action or failure to act to file an appeal. If you are appealing from a decision that would change, suspend, reduce, terminate the services you have been receiving, you can have them continue while the appeal is going on, but only if you file your appeal within ten calendar days of the mailing date of the written notice or, if you did not receive written notice at least ten days before the effective date of the action, by filing within ten days of being informed of the action. Keep the envelope the notice came in to prove the mailing date. The County will offer you a pre-hearing conference to

¹ The Adult Community Autism Program, also administered through the Bureau of Autism Services, is not a waiver program, but a four-county pilot program (Dauphin, Cumberland, Lancaster and Chester), serving 200 people, that integrates physical and behavioral health and community services, becoming the participant's health plan.

discuss the issues prior to hearing. You can choose to attend it or not. The Regional Office will review the appeal and may take steps to resolve the matter with the parties. If it is not resolved, DPW's Bureau of Hearings and Appeals will hold a hearing and render a decision within 90 calendar days of the date on which you filed your appeal (unless the hearing was delayed by your request for a continuance). If you are dissatisfied with the result, you can appeal through a request for reconsideration to the Secretary of Public Welfare. If you are not satisfied with that decision, you can appeal it to Pennsylvania Commonwealth Court. You can also reapply for the waiver or for services.

If you are denied the Adult Autism Waiver, or if actions are taken to deny new or additional services, or to suspend, reduce or terminate existing services, you will receive a written notice from the Bureau of Autism Services. The notice must include a statement of your appeal rights. You may request a Fair Hearing from the Bureau, and if, as above, you do so within ten days of the denial, existing services will continue for the duration of the appeal. The procedure is otherwise the same as the one for Intellectual/Developmental Disability Waivers.

VIII. SSI AND SSDI

What are they?: Supplemental Security Income ("SSI") and Social Security Disability Insurance ("SSDI") are both cash benefit programs administered through the Social Security Administration. Other than that, they are quite different. SSI is an income support (welfare) program based on an individual's income and assets or, for dependent children, on their and their family's income and assets. Disability is part of the formula for determining eligibility, especially for adults without dependent children, but low income is the primary determining factor. SSDI is a Social Security program that provides a monthly cash benefit to an individual who is disabled and unable to engage in substantial gainful employment (or, if a child, would be if she had the same disabilities as an adult). Like Social Security itself, it is based on an individuals' earning record. SSDI eligibility does not depend on an individual's or family's assets or unearned income (such as interest or dividends), but does care about the individual's earned income. Adults who become unable to engage in substantial gainful employment can apply for SSDI based on their own earning records. Disabled children of wage earners, if the children became disabled before their 22 birthdays, can apply for SSDI based on their parent's earning record, and become potentially eligible to receive SSDI when that parent becomes eligible to receive benefits from Social Security, either because of retirement, the parent's own disability, or the parent's death.

Who is eligible for them? See above.

What services do they provide? The benefit is a monthly cash amount, based either on the amount allotted by the governmental program and the

individual's income (in the case of SSI) or on the wage earner's earning record (in the case of SSDI).

How can I get them? Application for either is made through the local Social Security office.

What can I do if services are denied? In Pennsylvania, the next step is the filing of a written request for an Appeal Hearing to the Social Security Office, either online, through a written form (HA-501), or by letter. The written appeal must be filed within 65 calendar days of the date on the decision letter that provides notice of the denial. It is advisable to have legal representation for these appeals, especially if the denial is based on a dispute about the individual's ability to engage in substantial gainful employment.

IX. THE OFFICE OF VOCATIONAL REHABILITATION ("OVR")

What is it?: OVR is the state agency charged with the responsibility of assisting people with disabilities to train for, obtain, and maintain employment.

Who is eligible for it? Any adult Pennsylvanian with a disability that causes a substantial problem in preparing for, getting, or maintaining a career, and who wants to work is potentially eligible for services. When you apply, OVR will assign a vocational rehabilitation counselor who will gather information and arrange for needed medical examinations and testing, at no cost to you. OVR will then determine if you meet the eligibility criteria and if you can benefit in terms of employment outcome from the services OVR can provide.

What services does it provide? Services are provided to help overcome or lessen your disability or directly prepare for a career. Your career goal will be determined working with your counselor, and a plan of action, called an Individualized Written Rehabilitation Program ("IWRP"), will be developed. Services may include diagnostic services, counseling, restoration services, training, placement, room and board, transportation, occupational tools, licenses and equipment, home modifications, van and car notifications, personal care assistance, job site modifications, independent living training, and communication services and devices. Diagnostic, evaluation, counseling, and job placement services are free of charge. Depending on your income, there may be charges or co-pays for other OVR services. Evaluation and counseling services are an entitlement. The other services are available based on OVR's available funding. If OVR does not have enough money to serve everyone who is eligible, it follows an Order of Selection that serves individuals with the most severe disabilities first. You may be placed on a waiting list.

How can I get them? Application is made through the district OVR office responsible for the county you live in. You can apply in person or by calling for a meeting or an application. Usually, an eligibility decision will be made within 60 days of your application for services.

What can I do if services are denied? If you are dissatisfied with OVR services for any reason and cannot resolve the issue with your counselor, you can file a written appeal requesting a hearing before an impartial hearing officer. A written request for hearing must be filed within 30 days of the disputed decision or action. The written request for an impartial hearing must be mailed to or filed with the Director, Bureau of Program Operations, Office of Vocational Rehabilitation, Room 1310, Labor and Industry Building, Seventh and Forster Streets, Harrisburg, PA 17120. An impartial hearing officer will be assigned to hear your case. You will also be given the opportunity to have an informal administrative review prior to the hearing. The Client Assistance Project (“CAP”) can help you with the appeal process at no charge. You can reach CAP at 888-745-2357, 1617 JFK Boulevard, Suite 800, Philadelphia PA 19103.